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1115 Waiver Comments

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Thank you for the opportunity to present comments on the goals and strategies of the Illinois Medicaid 1115 Waiver. Illinois NOFAS (Illinois affiliate of the national Organization on Fetal Alcohol Syndrome) represents individuals on the spectrum of Fetal Alcohol Spectrum Disorders and their care givers.

FASD has never been included in the State's Wavier system and this current Medicaid Transformation 1115 Waiver could be a step in that direction. The prevalence of FASD in school age children is 2 – 5% (according to a study published by Dr. Philip May of New Mexico). CDC estimates that 1% of live births have an FASD. Apparently, FASD is one of the most prevalent neurodevelopmental conditions that is present in the community and affects every aspect of the society. Over 95% of those affected are not being accurately diagnosed in time and the one's that do get the diagnosis are not found to be eligible for services. FASD is 100% preventable and remains a multigenerational problem. It has been reported that about 80% of individuals in the foster care system have been exposed to alcohol prenatally and therefore are on the spectrum of FASD. Approximately, 30 – 40% individuals in the juvenile justice system are considered to have FASD. A large number of individuals who have substance abuse issues have undiagnosed Fetal Alcohol Syndrome. FASD is one of the most underreported and misdiagnosed condition. Until now individuals with FASD could not qualify for mental illness or intellectual disabilities services.

The recently released DSM-V has included FASD as ND-PAE (Neurodevelopmental Disorder Associated Prenatal Alcohol Exposure) under the category of " Other Neurodevelopmental Disorder" and also has a description under conditions for further study. According to NOFAS, it costs at least 2.0 million to care for one person with FASD over the life time. In a 1996 study of adults with an FASD conducted by University of Washington: over 50% had trouble finding a job, 60% had trouble keeping a job, over 80% were unable to live independently and were living

with their families, group homes, institutions and / or in homeless shelters. Over 80% were found to be ineligible for social services, 66% had difficulty in receiving medical care, 47% had difficulty staying out of trouble with the law and managing their leisure time, effectively. More than 56% had difficulty initiating and maintaining relationships. It is extremely important that individuals with an FASD are made eligible for receiving services under Medicaid and providers become eligible for services for this condition. This will not only make clinicians aware of the condition but also the community becomes aware of its being 100% preventable.

Our recommendations are to include FETAL Alcohol Spectrum Disorder and or ND-PAE as a condition eligible for a waiver.

**The services must intensify and include:**

Billable Screening, assessment and evaluation services for the condition

Billable treatment programs

Integrated mental health, addictions and primary care

Peer and caregiver education about the condition and support services

Case management and care coordination

Intensive outpatient services

Mentoring programs

Employment and education services

Housing with supportive services and transportation

Daily living skills and assistance with personal care as needed

Skill building and socialization services

Assertive Community Treatment

Assistance with budgeting and time management

Assistance when come in contact with the law, alternative sentencing and community support reentry programs

Crisis intervention services

Long term care

NOFAs Illinois recognizes that awareness and education about the condition is fundamental to early identification and effective treatment to improve long term outcome. Caregivers need respite services and assistance with transportation and sometimes in-home care. Lack of knowledgeable professionals, lack of adequate services, resources and programs leave these families exhausted and broke. Many individuals with FASD are unable to complete high school and so fall through the cracks and end up in correction as repeat offenders, become homeless or are institutionalized.

Based on the concept paper, we offer the following recommendations for the 1115 Waiver and our willingness to provide assistance in developing FASD related supports and services in the State of Illinois.

### **HCBS infrastructure, choice and coordination**

FASD remains an 'Invisible Disability / Epidemic' unless a spotlight is brought on it. The state of Alaska has developed a very effective program that has reduced the prevalence of FASD. Canada has been very proactive in utilizing resources in early identification and providing support and programs for individuals with FASD and pregnant mothers. FASD requires the expansion of its home and community-based infrastructure, especially for this population as they have complex health and behavioral health needs. While the development of brain is compromised due to prenatal alcohol exposure, other organs and systems are affected. This is part of a model called "Family Moving Forwards" developed at the University of Washington. This program services for our beneficiaries and ensure that services are based on individual needs and preferences rather than disability.

### **Population health**

Bringing awareness to FASD by including the condition in the 1115 Waiver will help expand the capacity of the healthcare delivery system to take responsibility for the health of a population, with a focus on prevention of FASD, primary care and wellness. FASD is the only cause of intellectual disability that is 100% preventable.

## **Supporting employment and housing**

As stated earlier more than 80% of individuals affected with FASD are unable to live independently and remain employed. This puts a huge burden on society and care givers.

Development of a statewide program for individuals with FASD, birth mothers, care givers, and providers to advocate for a system that meets the needs for these individuals.

## **Delivery system transformation**

Education and training on FASD to multidisciplinary teams / care coordinators and behavioral health providers that are involved in CCE & ACE models. These integrated service delivery model can reduce the life time cost of caring a person with FASD from 2 million dollars to a fraction of the cost. These individuals can be productive member of the society rather being dependent on the care.

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